No. 88-1377

IN THE
Supreme Court of the United States
OCTOBER TERM, 1988

LOUIS SULLIVAN, Secretary of the United States Department of Health and Human Services,
Petitioner,

v.

BRIAN ZEBLEY *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Third Circuit

---

BRIEF OF *AMICI CURIAE* AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY, AMERICAN PSYCHIATRIC ASSOCIATION, ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES, NATIONAL ALLIANCE FOR THE MENTALLY ILL, NATIONAL ASSOCIATION FOR RIGHTS PROTECTION AND ADVOCACY, NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL RESOURCES, AND NATIONAL MENTAL HEALTH ASSOCIATION IN SUPPORT OF RESPONDENTS

LEONARD S. RUBENSTEIN
Mental Health Law Project
2021 L Street, N.W., Suite 800
Washington, D.C. 20036
(202) 467-5730
Counsel for Amici Curiae

TABLE OF CONTENTS

TABLE OF AUTHORITIES

Cases: Page

Statutes and Regulations:

TABLE OF AUTHORITIES–Continued

Page

Other Authorities:

TABLE OF AUTHORITIES–Continued

Page

TABLE OF AUTHORITIES–Continued

Page

IN THE

Supreme Court of the United States

OCTOBER TERM, 1988

No. 88-1377

LOUIS SULLIVAN, Secretary of the United States
Department of Health and Human Services,
Petitioner,

v.

BRIAN ZEBLEY *et al.*,
Respondents.

On Writ of Certiorari to the United States Court of Appeals for the Third Circuit

---

BRIEF OF *AMICI CURIAE* AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY, AMERICAN PSYCHIATRIC ASSOCIATION, ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES, NATIONAL ALLIANCE FOR THE MENTALLY ILL, NATIONAL ASSOCIATION FOR RIGHTS PROTECTION AND ADVOCACY, NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL RESOURCES, AND NATIONAL MENTAL HEALTH ASSOCIATION IN SUPPORT OF RESPONDENTS

Amici curiae, organizations of mental health and mental retardation professionals, families and advocates with a special concern for children, address a single question in this brief: Whether the exclusive use of the Secretary's "listings"

of impairment to assess eligibility for Supplemental Security Income ("SSI") benefits for children with mental disabilities, without a separate assessment of residual functional capacity, violates the Social Security Act. Children with mental disabilities represent half of all SSI disabled children.[1] The methods of assessment of disability among these children illustrate the arbitrariness of the approach the Secretary uses for disability evaluation in all children.

The parties have consented to the filing of this brief. Letters of consent are attached.

INTEREST OF *AMICI CURIAE*

Amici are organizations that share a strong commitment to meeting the needs of children with mental disabilities, especially those who live in poor families. They all work to assure that programs established by Congress are faithfully carried out by those responsible for their administration.

The American Academy of Child and Adolescent Psychiatry is a national professional association of more than 4,100 child and adolescent psychiatrists. Its members are physicians who have completed a general psychiatry residency and two years' additional residency training in child and adolescent psychiatry. This medical discipline is concerned with the prevention, diagnosis and treatment of developmental and psychiatric disorders in children, adolescents and families.

The American Psychiatric Association, founded in 1844, is the nation's largest organization of physicians who specialize in psychiatry, with more than 35,000 members. The Association and its members have been actively involved in the process by which the Secretary of Health and Human Services determines whether mentally ill persons are entitled

---

[1] House Committee on Ways and Means, *Background Material and Data on Programs within the Jurisdiction of the Committee on Ways and Means*, 101st Cong., 1st Sess. 699-700 (1989).

to Social Security and SSI disability benefits. It has advised Congress and the Secretary concerning standards and procedures that should be used in benefits determinations and its individual members participate in the treatment and evaluation of disability applicants.

The Association for Retarded Citizens of the United States, with 160,000 members and 1,300 local chapters, is the largest voluntary organization devoted to securing the rights of and effective services for the approximately 6 million adults and children who are mentally retarded. It participates actively in formation of public policy concerning citizens with mental retardation and has been recognized in Congress, in state legislatures, in administrative proceedings and in the courts, as fairly and fully representing the interests of citizens with retardation and their families. It has worked with the Social Security Administration for decades on programs affecting people with mental retardation.

The National Alliance for the Mentally Ill represents 60,000 parents, spouses, siblings and children of mentally ill persons, as well as mentally ill clients themselves. It is organized into state alliances and more than 800 local affiliates. As a family movement, it provides self-help and supportive services, conducts a vigorous education campaign against the stigma of mental illness, and advocates for increased research on the causes and cures of mental illness and improved treatment and rehabilitative services for those afflicted with serious mental illness.

The National Association for Rights Protection and Advocacy (NARPA) is the only national organization that addresses both mental health and retardation issues and that includes in its membership a broad spectrum of state departmental administrators, specialists in treatment and habilitation, professional advocates, and former and present recipients of mental health and retardation services. NARPA has been invited to testify on several occasions before the United

States Congress concerning the legal rights of people with mental handicaps and has filed *amicus* briefs in this Court.

The National Association of Private Residential Resources represents about 600 agencies which together provide residential services for more than 35,000 children and adults with developmental disabilities. Its goal is to represent and assist providers of residential services in meeting the needs and improving the quality of life of people with mental retardation and other developmental disabilities. The people these agencies serve need public support to obtain services to help them become more independent.

The National Mental Health Association is a citizen advocacy organization concerned with all aspects of mental illness and mental health. Since its formation in 1909, the NMHA has worked to improve the care and treatment of persons with mental illness, promote mental health and prevent mental illness. The NMHA's 650 local chapters and state divisions and its more than one million volunteers and supporters work toward these goals through a wide range of activities in social action, education, advocacy and public information.

STATEMENT OF THE CASE

The number of children with mental disabilities continues to grow. Studies conducted by the Congress' Office of Technology Assessment estimate that mental impairment is present in 12% of the 63 million American children under the age of 18. Nearly half of these 7.5 million children are considered severely disordered or handicapped by their impairment.[2] Among inner-city children, who are often

[2] Office of Technology Assessment, Children's Mental Health: Problems and Services – A background paper (Publication No. OTA-BP-H-33) (1986).

exposed to severe social and financial deprivation, the rate of disability is even higher.[3]

Children burdened by poverty and disability are eligible to seek children's benefits under the Supplemental Security Income (SSI) program. SSI, created under Title XVI of the Social Security Act, 42 U.S.C. § 1382*e et seq.* (1982), provides subsistence income to needy disabled, blind and aged persons, including poor children under the age of 18 who have disabilities. The children's SSI disability program is designed to provide indigent families with the extra financial resources they inevitably need to raise children with disabilities: money for special diets, for transportation to clinics, physicians and rehabilitation facilities, for special services not covered by any medical assistance program, for skilled child care and for a range of individual needs too numerous to catalogue. Further, the extraordinary time demands required to meet the child's needs often limit the parents' ability to work, rendering the family dependent on financial assistance afforded by SSI. Finally, the child's eligibility for critically important medical care funded through Medicaid often hinges on receipt of SSI benefits.[4] Yet only a small fraction of indigent children with mental disabilities receive SSI: 280,000 nationwide.[5]

[3] National Institute of Medicine, Research on Children and Adolescents with Mental, Behavioral and Developmental Disorders: Mobilizing a National Initiative (1989).

[4] A recent survey of four states found that while SSI disabled children accounted for between one and five percent of the Medicaid child population, they accounted for between 14 and 35 percent of Medicaid expenditures for children. Expenditures for inpatient hospital care are up to seven times greater for SSI disabled children than for children whose Medicaid eligibility derives from receipt of Aid to Families with Dependent Children. Rymer & Adler, *Children and Medicaid: The Experience in Four States* (1987).

[5] United States Department of Health and Human Services, Social Security Administration, *Social Security Bulletin, Annual Statistical Supplement, 1988*, Table 9.B8. The number of children potentially eligible for SSI is not

The SSI Program for Children

In fashioning the disability program for children, Congress directed the Secretary of Health and Human Services to create eligibility standards that would cover disabling impairments in children if they were of "comparable severity" to a disabling impairment in an adult. The statute provides:

> An individual shall be considered to be disabled for the purpose of this Title if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months (or, in the case of a child under the age of 18, if he suffers from any medically determinable physical or mental impairment of *comparable severity*). . . .

42 U.S.C. § 1382c(a)(3)(A) (1982 & Supp. IV 1986) (emphasis added).

To implement that requirement, the Secretary has created eligibility rules, called "listings," consisting of a set of signs, symptoms and certain functional deficits which the Secretary considers disabling. *Bowen v. City of New York*, 476 U.S. 467, 470-71 (1986). Only if the child's condition "meets" these listings is he or she considered disabled.[6] 20 C.F.R. § 416.924.

---

known. Fox and Greaney, using data from the National Health Interview Survey, estimate that only 10 percent of eligible children receive benefits, though they state that the estimate is derived from a relatively small sample. Fox & Greaney, *Disabled Children's Access to Supplemental Security Income and Medicaid Benefits* 9 (1988) (lodged with the Clerk).

[6] The Secretary also theoretically allows benefits for individuals with conditions that do not meet the listings, but are determined to be medically equal to a listed impairment. The "equals" concept, however, is almost never used in mental impairment cases. Jt. App. 77-78. Further, heightened intensity in one symptom can never be used to justify an "equals" determination if all other criteria for the listing are not met. Jt. App. 81, 255.

The Secretary also uses listings to determine disability in adults, but the adult listings play a very different role in the determination process. The adult listings are an administrative shortcut, a device to decide claims favorably to claimants without full development of the evidence. *City of New York*, 476 U.S. at 471. If an adult with a severe mental or physical impairment does not have a condition that "meets" the listings, the Secretary engages in two kinds of further evidentiary development and evaluation.

First, he gathers evidence to consider in detail the person's "residual functional capacity." That is defined by the Secretary as "what you can do despite your limitations." 20 C.F.R. § 416.945(a). The assessment of residual functional capacity is an objective and highly individualized assessment of the person's actual ability to function, "including limitations that go beyond the symptoms of [the person's] medical condition." *Id.* For people with severe mental impairments who do not meet the listing, this assessment is "crucial." Jt. App. 181. Second, the Secretary investigates the person's vocational profile through an examination of age, education and prior work experience. 20 C.F.R. § 416.960.

For an adult claimant, therefore, failure to have a listed condition has no adverse consequences. Rather, it merely triggers the next steps in the evaluation process, notably the individualized evaluation of the person's ability to function appropriately in a variety of settings. If a child's condition does not meet the listings, however, his claim is denied.

The Disability Assessment Rules for Children with Mental Disabilities

The Secretary's reliance on listings alone for children's disability claims derived from a more general theory of disability assessment adopted by SSA in the late 1970s.

According to that theory, functional limitations could be inferred or derived from medical data, such as signs, symptoms and laboratory findings, rather than by actual assessment of those limitations. Under this reasoning, the listings allowed evaluation of these medical criteria, so the separate residual functional capacity determination required in the regulations to ascertain actual ability to work was "redundant." *City of New York v. Heckler*, 578 F. Supp. 1109, 1116 (E.D.N.Y. 1984), *aff'd*, 742 F.2d 729 (2d Cir. 1985), *aff'd sub nom. Bowen v. City of New York*, 476 U.S. 467 (1986). As a consequence, even for adults, the Secretary relied exclusively on what the Secretary calls "medical" factors, by which he meant excluding the assessment of residual functional capacity.[7] He therefore denied the claim of any person whose condition did not meet the level of severity specified in one of the mental impairment listings. *Id.*, 578 F. Supp. at 1115. In addition, the theory held that functional limitations were only relevant to the extent that *all* functioning was impaired.

When the childhood disability rules were promulgated in 1977, the Secretary applied the same medical and scientific assumptions. Thus, upon promulgating the children's listings, the Secretary stated: "We agree that for those impairments common to both adults and children the proposed Listing corresponds to the adult Listing, with modifications of the adult criteria, where necessary, to take into account the different impact on children." 42 Fed. Reg. 14706 (March 16, 1977). Instead of the "covert" exclusion of the residual functional capacity assessment from the evaluation process, however–the policy for adults, *City of New York*, 476 U.S. at 474–elimination of this assessment was explicitly set forth in the rules for children.

---

[7] The Secretary's use of the term "medical" to exclude the assessment of residual functional capacity, e.g., Pet. Br. 38, is confusing and, in fact, contrary to the definition of residual functional capacity in the regulations. The regulations state flatly: "Residual functional capacity is a medical assessment." 20 C.F.R. § 416.945(b).

The four childhood mental impairment listings thus follow the adult listings then in effect: organic brain syndrome, psychotic disorders, non-psychotic disorders and mental retardation.[8] Further, following the thinking applied to adult disability assessment, the listings either exclude evidence of functional limitations altogether or require that all areas of functioning be impaired.

Accordingly, the children's listing for chronic brain syndrome, 20 C.F.R. Part 404, Subpart P, Appendix 1 § 112.02, Jt. App. 232, is modeled on the old adult listing for chronic brain syndrome, and requires "arrest of developmental progression for at least six months or loss of previously acquired abilities." Notably, complete arrest in development is required; no consideration is given to specific delays in development, such as in language, gross and fine motor skills or social interaction, and degree of functional impairment. In other listings, for psychotic and non-psychotic psychiatric disorders in children, functional limitations are considered, but only to the extent that *all* aspects of functioning are impaired, including marked restriction in performance of daily age-appropriate activities, constriction of age-appropriate interests, deficiency of age-appropriate self-care skills and seriously impaired ability to relate to others. Jt. App. 232-233.

These rules are extremely restrictive. For example, the following children would not meet the listings:

- a child who is seriously depressed, anxious or psychotic, but is able to dress himself and to eat unassisted or with minimal assistance.
- a severely hyperactive child with a secondary behavioral communication disorder, but who retains some self-care skills.

---

[8] On August 14, 1989, the Secretary proposed new rules for evaluating mental impairment in children. 54 Fed. Reg. 33238 (Aug. 14, 1989).

- a child with an IQ between 60 and 69 who has severe behavioral, perceptual or communication problems, but who does not suffer a separate and independent impairment as well (neurological impairments such as severe perceptual problems, poor visual-motor coordination and severe communication problems are not considered separate because some experts consider them related to the retardation).
- an infant or toddler who, though showing severe developmental delays, does not fail to achieve *all* developmental milestones.
- a child with severe emotional and behavioral disorders who has self-care skills.

Highly dissatisfied with the medical and scientific bases of the old mental impairment disability evaluation criteria, Congress in 1984 ordered the Secretary to write new ones. Social Security Disability Benefits Reform Act of 1984, 42 U.S.C. § 421 note (Supp. IV 1986). Pursuant to this mandate, the Secretary issued new assessment rules for adults, 50 Fed. Reg. 35038 (Aug. 28, 1985), Jt. App. 179-199, including both listings and residual functional capacity guidelines, which significantly altered the criteria for evaluation of disability in adults. Recently, the Secretary issued proposed new listings for children with mental disabilities, 54 Fed. Reg. 33238 (Aug. 14, 1989), but these rules, if adopted, still do not require a separate residual functional capacity assessment.

SUMMARY OF ARGUMENT

The Secretary's approach to assessing mental disability in children violates the statutory requirement that the Secretary pay benefits to a child whose impairment is of "comparable severity" to that of an adult. While the Secretary has considerable latitude in writing regulations and standards, they must still be "reasonable and proper," 42 U.S.C. § 405(a) (1982), a phrase construed by this Court to mean neither

arbitrary nor capricious. *Bowen v. Yuckert*, 482 U.S. 137 (1987); *Heckler v. Campbell*, 461 U.S. 456, 466 (1983).

The Secretary's approach is contradictory. He acknowledges that severity of disability in children must be "measured according to functional limitations imposed" by an impairment, 54 Fed. Reg. 33241 (Aug. 14, 1989), *see also* Pet. Br. 38, but nevertheless excludes from consideration "the individual child's ability to function as such." Pet. Br. 42. Indeed, he goes so far as to deny children even the opportunity to show that their functioning is so impaired that they should be considered disabled. The process amounts to a perverse game of chance, depending not on the degree of disability, but on the presence or absence of certain signs or symptoms or functional limitations that the Secretary happens to include in the listings, from which he deduces disability.

This inconsistency is not a product of a dispute concerning the meaning of "comparable severity," but of the assessment methods necessary to carry it out. For 15 years, the Secretary has recognized–as recently as August, 1989, in proposed new listings for mental impairments, 54 Fed. Reg. 33241 (Aug. 14, 1989)–that disability in children, like disability in adults, must be defined in functional terms. Yet he insists that he can somehow figure out the degree of the child's functional limitations even as he excludes individualized evidence showing precisely what those limitations are.

The Secretary's refusal to perform a residual functional capacity assessment stems from a theory of disability assessment that has never been accepted by anyone in the field. It has been found arbitrary by the courts, *see Bowen v. City of New York*, 476 U.S. 467 (1986), and has been condemned by clinicians, researchers and the Congress. To be consistent with the statutory definition, the Secretary must engage in a residual functional capacity assessment for children. Indeed, for children with mental disabilities, individual functional assessment may be even more important than it is for adults.

That is because impairments have an enormously variable functional impact on individual children. As a result, the disability assessments used by professionals–but eschewed by the Secretary–rely far more heavily on evaluations of functioning than on signs, symptoms and laboratory findings.

The regulations, by excluding a residual functional capacity assessment for children, are therefore arbitrary and capricious.

ARGUMENT

THE SECRETARY HAS VIOLATED THE SOCIAL SECURITY ACT BY REFUSING TO ADHERE TO A FUNCTIONAL TEST OF DISABILITY.

This case is a reprise of *Bowen v. City of New York*, 476 U.S. 467 (1986). In each case the issue concerns the Secretary's decision to forego the assessment of a person's functioning that he recognizes as necessary to determine whether that person is disabled. In *City of New York*, the Secretary's error was to forego the functional assessment of mental disability in adults mandated in his own regulations and to substitute in its place a presumption that anyone whose condition was not serious enough to meet the criteria stated in the listing was not disabled. 476 U.S. at 473-75. Here, the mistake is to preclude, by regulation, the functional assessment that is essential under the Secretary's own definition of disability.

A. Functional Assessment Is the Central Ingredient in the Disability Determination.

The evaluation of a person's functional restrictions is the core of the evaluation of mental disability under the Social Security Act. *See Bowen v. Yuckert*, 482 U.S. 137 (1987); *Heckler v. Campbell*, 461 U.S. 456, 459-60 (1983). Rather than taking a strictly diagnostic approach, the disability program focuses on an assessment of the person's actual capacity to perform

relevant functional tasks. *Bowen v. City of New York*, 476 U.S. at 471. The Secretary's regulations recognize that "severity is assessed in terms of the functional limitations imposed by the impairment." Jt. App. 182. For adults, this assessment is contained not only in the listings, but in the fourth step of disability adjudication process, the "residual functional capacity" assessment, which "measures the claimant's capacity to engage in basic work activities." *Id.*[9] This assessment, the Secretary has acknowledged, is "crucial." Jt. App. 181.

Functional criteria are equally critical for children. From the start of the SSI children's disability program, the Secretary accepted that childhood disability must be defined by reference to reduced levels of functioning. Accordingly, in the first instructions issued in 1973 about the SSI children's disability program, the Secretary acknowledged that "disability must be defined in terms of the primary activity in which they engage, namely growth and development, the process of maturation." Jt. App. 90. The following year, the Secretary issued more detailed guidelines on what he meant by "the process of maturation" and its relationship to childhood disability. He determined that he would focus on four discrete areas, all of which require an evaluation of the child's functioning. These were:

1. growth–increase in size and maturation of physical and functional characteristics;
2. learning;
3. mastering basic skills; and
4. emotional and social development.

Jt. App. 96. He added that the emphasis is on the "impact of the impairment on the child's life." Jt. App. 96.

---

[9] The first three steps of the evaluation are designed to identify those who clearly are not entitled to benefits, those whose impairments are not severe or who are working, and those who are obviously disabled and entitled to benefits. *City of New York*, 476 U.S. at 471.

In 1977, when the children's disability listings were promulgated, the Secretary reiterated his commitment to a functional definition of disability. He stated that, when viewed as a whole, the standards for childhood disability must fairly and reasonably be calculated to identify impairments that "have a severe impact on a child's development in one form or another." 42 Fed. Reg. 14705 (March 16, 1977). The Secretary elaborated that the experts on whom he relied "placed primary emphasis on the *effects* of physical and mental impairments in children, the *impact* on the child's activities, and the *restrictions* on growth, learning and development imposed on the child by the impairments." *Id.* (emphasis added). This approach follows from the enormous variability in the impact a particular impairment has from one child to another.

The Secretary's own definition of comparable severity follows from this approach. It holds that the impairment must have an "impact on the child's development to the same extent that the adult criteria have on an adult's ability to engage in substantial gainful activity." *Id.*[10] The Secretary has acknowledged that to be considered substantively "comparable" within the meaning of the statute, the standards applied to children with disabilities must be true to a functional and developmental understanding of disability. Preface to Children's Listings, 42 Fed. Reg. 14705 (March 16, 1977). Thus, according to the Secretary, the rules for children, like those for adults, must be premised on a medically and

[10] Even the two lower court cases which the Secretary relies upon to support his position here, far from permitting the Secretary to exclude relevant functional and developmental criteria of disability, construed childhood disability in functional terms. In *Hinckley v. Secretary*, 742 F.2d 19 (1st Cir. 1984), the court explicitly referred to the Secretary's intent to examine the "effects" the impairment has on the child. *Id.* at 23. Similarly, in *Powell v. Schweiker*, 688 F.2d 1357 (11th Cir. 1982), the court referred to mental impairments as among those the Secretary agreed must "be evaluated in terms of the child's ability to function," 688 F.2d at 1360 and n.9.

scientifically respectable concept of the functional and developmental nature of childhood disability.

Indeed, the Secretary concedes now that "comparable severity" is defined in terms of an impairment's *impact* on a child–that is, how it affects his ability to function. Pet. Brief 37 (measure "impact" of impairment); 38 (measure "severity and impact"); 39 ("impact of the impairment on growth, learning and development"). The Secretary's most recent proposed rules for assessing mental impairment in children state flatly that "[i]n childhood cases, as with adults, *severity is measured according to functional limitations imposed by a medically determinable impairment*." 54 Fed. Reg. 33241 (Aug. 14, 1989) (emphasis added.)[11] These are enormous concessions, because the meaning of "comparable severity" is no longer at issue. Accordingly, contrary to the Secretary's position, deference to his interpretation of the statute in defining "comparable severity" is no longer at issue.

What is at issue is the Secretary's method of assessing functional loss, particularly his refusal to collect or, if he has collected it, to consider the very evidence necessary to assess functional loss in a particular case. At the same time that the Secretary recognizes that the essential measurement of disability is "impact" of an impairment on a child's functioning, he deliberately *prevents* the child from having the opportunity to show that impact through evidence of reduced functioning beyond the criteria in the listings.

Instead, as he candidly states, he relies exclusively on what he terms "medical factors alone," Pet. Br. 38, by which he means signs, symptoms, diagnoses and laboratory findings from which he *infers* functional loss. There is "no

[11] The contrast between the Secretary's position in the proposed new rules and his position before this Court could hardly be more striking. For example, his proposed rules state that "school records are a rich source of data," 54 Fed. Reg. 33243 (Aug. 14, 1989). His brief, however, says that "special education" is "not considered as such." Pet. Br. 40.

individualized consideration" of reduced functioning. Pet. Br. 36. He excludes competent psychiatric, psychological, social work, school and parental evidence "on the individual child's ability to function as such." Pet. Br. 42. There is therefore no place in the process even to receive evidence of the impact of the impairment on the child beyond what is contained in the listings. Unlike *Heckler v. Campbell*, 461 U.S. at 467, which upheld decisional rules that gave the claimant "ample opportunity" to present evidence relating to his own abilities, the rules here provide no opportunity at all for such a showing.

This approach is not only contradictory, but self-defeating. It is like trying to figure out what is wrong with a car by looking at its parts, but not listening to the owner describe what the car is doing wrong. The Secretary's job is not to be Sherlock Holmes, deducing from cryptic clues, but to design and carry out assessments that illuminate the degree of a child's functional limitations. The impact of impairments can only be determined by looking at an individual child's functional abilities.[12] The notion that listings alone can substitute for an individualized functional assessment has already been utterly repudiated by science, by courts and by Congress.

B. The Medical and Scientific Assumptions Underlying the Assessment Rules Are Baseless.

The contradiction between the functional definition of disability and the Secretary's virtually exclusive reliance on non-functional criteria for evaluation is a product of serious scientific and medical error as well as administrative irregularity. The methodology the Secretary uses is based on the erroneous assumption that functional deficits could be inferred from what the Secretary calls "medical evidence" alone–from signs, symptoms and laboratory findings. This

[12] Vocational factors, by contrast, are properly excluded from the assessment of disability in children, who have no work history.

assumption was, even at the time the listings were adopted, insupportable.[13] It was finally abandoned by the Secretary when he promulgated new regulations for the evaluation of mental disability in adults in the face of judicial decisions, medical and scientific outcry and congressional pressure. Yet the repudiated approach remains embodied in the Secretary's approach to disability assessment in children.

1. *Medical Criteria Alone Cannot Assess Functional Restrictions.*

The theory that functional limitation can be inferred from signs, symptoms and laboratory findings, making a determination of residual functional capacity unnecessary, while zealously applied by SSA to both child and adult disability claims, never found support in medical and scientific research.[14] When challenged, it was found arbitrary:

> Scientific research and clinical data in the fields of psychiatry and rehabilitation psychology demonstrate that the Listing of mental impairments does not measure ability to work. Neither the symptoms contained in the A portion of the Listing, nor the daily functional ability provisions contained in the B portion of the Listing, measures or predicts ability to work.

[13] *See* note 7, *supra*.

[14] Goldman and Manderscheid, *The Epidemiology of Psychiatric Disability*, in *Psychiatric Disability: Clinical, Legal and Administrative Dimensions* 14 (Meyerson and Fine, eds. 1987). *See also* Hamilton, *Social Security Disability Programs: How They Work for the Mentally Impaired*, in *Psychiatric Disability*, *supra*, at 417 ("Study and research in the area have not established such a direct relationship" between signs and symptoms and disability); Anthony and Jansen, *Predicting the Vocational Capacity of the Chronically Mentally Ill: Research and Policy Implications*, 39 Am. Psychologist 537 (1984); Goldman and Gattozzi, *Balance of Powers: Social Security and the Mentally Disabled, 1980-1985*, 66 Milbank Q. 531 (1988); Rubenstein, *Science, Law and Psychiatric Disability*, 9 Psychosocial Rehabilitation J. 7 (1985).

Mental Health Association of Minnesota v. Schweiker, 554 F. Supp. 157, 162 (D. Minn. 1982), *aff'd*, 720 F.2d 965 (8th Cir. 1983). Similarly, in *City of New York v. Heckler*, 578 F. Supp. 1109 (E.D.N.Y. 1984), *aff'd*, 742 F.2d 729 (2d Cir. 1985), *aff'd sub nom. Bowen v. City of New York*, 476 U.S. 467 (1986), the district court found: "Medical experts demonstrated to the court that the symptoms and restrictions of the listings of impairments do not measure an individual's capacity for work or his or her ability to withstand the stress of even the least demanding work." 578 F. Supp. at 1124. As a result of SSA's reliance on this erroneous theory, though, "an individualized, realistic assessment of ability to work [was] not performed at any stage of the sequential evaluation process." *Mental Health Association of Minnesota*, 554 F. Supp. at 160-61.

This fundamentally flawed approach led to adjudicative chaos. The district court in *City of New York* aptly described the havoc that followed the substitution of the listings for the functional assessment mandated both by professional practice and by law:

> SSA relied on bureaucratic instructions rather than individualized assessments and overruled the medical opinions of its own consulting physicians that many of those whose claims they were instructed to deny could not, in fact, work. Physicians were pressured to reach "conclusions" contrary to their professional beliefs where they felt, at the very least, that additional evidence needed to be gathered in the form of a realistic work assessment. The resulting supremacy of bureaucracy over professional medical judgments and the flaunting [sic] of published objective standards is contrary to the spirit and the letter of the Social Security Act.

Bowen v. City of New York, 476 U.S. at 474 n.5 (quoting district court findings). In *City of New York* alone, which covered only one state, in a three-year period more than 14,000

people were denied or terminated from benefits because of this rule.

The courts found that the medical criteria in the listings were an insufficient basis on which to render the assessment of a person's functioning that the Social Security Act required. They ordered that a realistic residual functional capacity assessment be made for each claimant who had a severe impairment.

After an extensive series of hearings and reports by the General Accounting Office, Congress addressed the same problem. It found "serious questions" about SSA's adjudication methods and noted that even "the Secretary has determined that a full scale re-evaluation of the Listings and current procedures is necessary." H.R. Rep. No. 619, 98th Cong., 2d Sess. at 15, 1984 U.S. Code Cong. & Admin. News 3052. Accordingly, § 5(a) of the Social Security Disability Reform Act of 1984, Pub. L. 98-460, 98 Stat. 1801, 42 U.S.C. § 421 note (Supp. IV 1986), mandated that the Secretary rewrite both the listings and the residual functional capacity guidelines. Congress underscored its criticism of the old approach by demanding that the new criteria "realistically" evaluate the claim of disability. 98 Stat. 1801.

The Secretary then completely overhauled his approach to adult mental impairment assessment. The Preface to the new rules utterly repudiates the Secretary's former approach to disability assessment. Rather than relying primarily, much less exclusively, on what the Secretary calls "medical" criteria, the Preface declares unequivocally that "severity is assessed in terms of the functional limitations imposed by the impairment." Jt. App. 182. Medical evidence is necessary only to establish the *presence* of a mental disorder. *Id.* The preface also warns that, because evidence of functioning is key, inferences drawn solely from medical evidence must be made with extreme care. For example, "mental status examination or psychological test data alone should not be used to accurately describe concentration and sustained ability to

adequately perform work-like tasks." Jt. App. 185. The new adult listings themselves, therefore, demand far greater attention to functional restrictions than did the old ones.

Equally important, the rules emphasize that, in view of the functional test of disability, *no* set of listings can capture the variety in the possible functional deficits an impairment can produce in an individual, nor can any set of listings provide an adequate opportunity for the individual to show the extent of functional loss. Jt. App. 181. Accordingly, despite the new and quite comprehensive functionally oriented listings,[15] the rules stress the "crucial" importance of the residual functional capacity assessment for a person whose impairment does not meet the listings. Jt. App. 180.

This approach belies the Secretary's suggestion that, if his approach is flawed, the attack properly should be directed at a particular set of listings, not at the absence of an individualized functional assessment (Pet. Br. 42). Precisely because of the variation in the impact of any particular impairment on any person, child or adult, the search for total comprehensiveness–whether in the existing rules or the proposed new listings–is doomed. No set of listings can meet the statute's requirement.

The Secretary has joined medicine and science in rejecting, for adults, the premises on which the disability rules were originally constructed. But the Secretary's brief acknowledges that disability assessment in children remains based on "medical factors alone" (Pet. Br. 38) and that severity is measured "in medical rather than functional terms" (Pet. Br. 40). Putting aside the odd and contradictory way the Secretary employs the term "medical" in his brief (after all, residual functional capacity is a "medical" assessment

[15] For example, the listings now take account of deficiencies in concentration and pace in a work-like setting and decompensation on the job. Jt. App. 179-99. Moreover, the categories of impairments have expanded from four to eight.

in the regulations[16]), the position cannot be squared with his own frequently articulated views or the mandates of the courts and the Congress. Yet the Secretary goes so far as to cite his 1977 statement that, contrary to his own new adult mental impairment regulations, his approach is "mandated" by the Social Security Act. *Id.* To reassert this rationale now in the face of the Reform Act and the new adult adjudication is virtually a confession of error.

2. *Functional Assessment Is as Critical for Children as for Adults.*

In determining the extent of a child's disability, there is no substitute for individualized functional assessment. Just as for adults, in assessing the overall impact of a developmental or behavioral impairment, mental health and mental retardation professionals attempt to assess the overall impact of the child's developmental, medical and behavioral problems on his day-to-day functioning in a variety of settings. The goal is not merely to provide a medical label for the child's problems, but to discover his needs and limitations. The critical assessment is to determine how his impairments limit his ability to function and ascertain the assistance necessary to meet the needs thus created. This is because a given diagnosis or medical evaluation, by itself, cannot necessarily specify any particular level of disability or course of treatment.

A number of factors render functional assessment even more important for children than it is for adults. Some problems, especially those in infants and young children, cannot be revealed by a single diagnosis or a psychometric instrument. For this reason, good disability assessments utilize a variety of means for evaluating specific skills and identifying disabilities and troublesome behaviors. Experts recommend a multi-disciplinary approach to the assessment

[16] *See* note 7, *supra*.

of the functional significance of developmental disability as it is manifested in individual cases.[17]

Further, evaluation procedures performed in clinical settings often fail to ascertain the actual severity of the disability because they cannot assess the child over a long enough time or in the actual settings in which he is expected to perform daily. "Procedures that are quick, simple and economical have not been demonstrated to be highly reliable or valid."[18] In other words, "Informal and standardized observations and questionnaires...are not very accurate for predicting behavior in the future or in other settings."[19] Accurate assessments of functional capacity cannot be determined by a single visit to a physician absent input from other sources as to the child's performance in other settings.[20] A child who has self-care skills and does well at home may be completely unable to adjust to the demands of school, for example. For school-age children, the three

---

[17] *See, e.g.*, Chess & Thomas, *Origins and Evolution of Behavior Disorders from Infancy to Early Adult Life* (1984); Crocker & Cullinane, *The Function of Teams*, in *Developmental-Behavioral Pediatrics* 990 (M. Levine ed. 1983); Foster *et al.*, *Screening for Developmental Disabilities*, 143 W.J. Med. 349 (Sept. 1985); Healy, *Screening for Disabilities*, 143 W.J. Med. 379 (Sept. 1985); Magrab & Lehr, *Assessment Techniques in Pediatric Psychology*, in *Handbook for the Practice of Pediatric Psychology* (J. Tuma ed. 1982).

[18] Frankenburg, *Infant and Preschool Developmental Screening*, in *Developmental-Behavioral Pediatrics* 927, 930 (M. Levine *et al.* eds. 1983). *Cf.* Foster *et al.*, *supra* note 17, at 355.

[19] Liptak & Chamberlin, *Clinical Assessment of Behavioral Performance or Adjustment*, in *Developmental-Behavioral Pediatrics* 916, 921 (M. Levine *et al.* eds. 1983).

[20] The behaviors and capacities a child displays in the physician's office may be quite different from those he displays at home or at school. "No single set of observations – be it a neurodevelopmental examination, an intelligence test, or parent or teacher reports – should be taken as the ultimate word. Instead, it is the compilation and integration of data from multiple sources that is likely to provide the most accurate assessment of development." Levine, *The Developmental Assessment of the School Age Child*, in *Developmental-Behavioral Pediatrics* 938, 939 (M. Levine *et al.* eds. 1983).

main areas that should be examined are academic performance, peer relationships in and out of school, and social functioning at home and at school. Other aspects of the child's functioning may also be relevant to specific disorders.[21] None of these can be gleaned from medical criteria alone (as the Secretary now uses that term), yet they are specifically excluded by the Secretary.

In addition, psychiatrists and developmental specialists may consider a child severely disabled for reasons other than their diagnosis. Some children may be significantly impaired in only one area of functioning, but unable to lead a normal life when compared to average children or to their own "baseline" (functioning prior to becoming ill or disabled). Other children may experience moderate to severe impairment in several areas of functioning, yet be much more like the average. The important point is that both kinds of children may be severely impaired.

Several disorders of low severity, moreover–none of which would, alone, completely disable a child–may be highly disabling when they occur together in a single child. Moreover, developmental experts agree that "children with multiple developmental or functional problems have been shown...to have more persistent difficulties than those with one problem."[22]

The total effect of several moderate or severe handicaps may be a more severe overall impairment in daily performance than one would expect, given the particular disabilities

---

[21] Puig-Antich & Rabinovich, *Major Child and Adolescent Psychiatric Disorders*, in *Developmental-Behavioral Pediatrics* 865, 866 (M. Levine *et al.* eds. 1983).

[22] Palfrey *et al.*, *The Identification of Children's Special Needs: A Study in Five Metropolitan Communities*, 111 J. Pediatrics 651, 676 (Nov. 1987).

viewed in isolation.[23] Often, such an additive disabling effect is best observed by challenging the child in settings in which he is expected to perform day-to-day (e.g., at home or at school), rather than confining the assessment to a clinical test designed to examine a particular skill or capacity.

Finally, the wide range of impairments considered typical of some developmental disorders makes it very difficult to assess children affected with those disorders based on medical criteria alone. For example, though autism[24] is considered a clinically recognizable problem, "the definitions for autism do not specify a specific disease or condition but rather a syndrome characterized by a large number of symptoms." A child need not present all of the symptoms in order to be diagnosed autistic, and children with very different symptomatologies are often diagnosed autistic.[25]

Some children labeled "autistic" display only a few of the behavior patterns characteristic of autism. Some possess

---

[23] Two experts note that "The specific or actual additive constraint to human development caused by the presence of more than one disability is obvious." Nelson & Crocker, *The Child with Multiple Handicaps*, in *Developmental-Behavioral Pediatrics* 828, 829 (M. Levine *et al.* eds. 1983).

[24] Childhood autism is "a developmental disability characterized by an onset before five years of age; a disturbance in the rate of appearance of physical, social, and communication skills; an abnormal response to sensation; absence or delayed development of speech or language; and abnormal ways of relating to people, objects, and events." Autistic children often do poorly on tests of intelligence, but autism is distinguished from mental retardation insofar as many autistic children have special "islands" of competence, and do better on a wider variety of intelligence tests than do children who are mentally retarded. Autism is distinguished from childhood schizophrenia, as well, mainly because autism has an earlier age of onset. "Autistic children require...treatment if they are to make adequate gains in communication, social, self-help, and academic skills." Christian, *Childhood Autism*, in *Developmental-Behavioral Pediatrics* 816, 827 (M. Levine *et al.* eds. 1983).

[25] Moreover, most treatment methods are symptom specific, since there are a wide variety of symptoms characteristic of autism and it is unlikely that a child will have all of them. Christian, *supra* note 24, at 816.

special abilities (like the "autistic savants" who have a particular area of competence or genius, despite overall disability). Others have severe deficits and no special skills.[26] Clearly, because some children with autism do have areas of special competence, an autistic child might well not meet the criteria under either the current or proposed listing.[27] Yet despite the variety of manifestations taken by childhood autism, it is considered by professionals to be a severely disabling illness. which warrants intervention according to the specific deficits displayed by the individual child.[28]

For these reasons, clinicians recognize that it is essential to assess individual behavior patterns rather than to focus attention on diagnosing the child or to argue about the precise definitions of developmental disabilities such as autism.[29] In fact, "[d]escription rather than diagnosis is the desired goal in most cases."[30] And because an initial diagnosis does not necessarily specify in great detail "the behavioral excesses and deficits of the individual child,"[31] individualized assessments must be made of the severity of the child's

---

[26] *Id.* at 822.

[27] One of the hallmarks of autism is withdrawal from social relationships and a lack of interest in events or people outside the self. Autistic children often relate to other people much as they would to mere objects. It is not unlikely, therefore, that an autistic child might experience marked restriction in performance of daily age-appropriate activities, constriction of age-appropriate interests, and impaired ability to relate to others, even though he might be able to care for himself in an age-appropriate manner.

[28] Christian, *supra* note 24, at 820, 821, 827. *See also* Introduction to *Major Handicapping Conditions*, *id.* at 756.

[29] *See* Christian, *Reaching Autistic Children: Strategies for Parents and Helping Professionals*, in *Coping with Crisis and Handicap* (A. Milunsky ed. 1981); and R. Koegel and L. Schreibman, *How to Teach Autistic and Other Severely Handicapped Children* (1981).

[30] Blackman & Levine, *A Follow-up Study of Preschool Children Evaluated for Developmental and Behavioral Problems*, 26 Clinical Pediatrics 249 (May 1987).

[31] Christian, *supra* note 24, at 820.

illness, based upon examination of the child's capacities in a variety of settings. Attempts should be made to ascertain the particular strengths and weaknesses of the individual child "and their relevance to his performance in life."[32]

We do not doubt the authority of the Secretary to vary his procedures for assessment of claims tailored to the characteristics and disabling effects of particular impairments. But he must use that authority in a manner that still respects a common underlying standard of disability and employs a methodology designed to elicit facts about the child relevant to that standard.[33] For children, the only method that respects the functional definition of disability requires an individualized assessment of functioning.

The Secretary's proposed new listings for children's mental impairments take a step in that direction by including more functional criteria. But the proposed listings are not –nor can they be–comprehensive. For example, they take no account of relatively common functional deficits such as inability to attend, impulsivity or hyperactivity. Given the impossibility of creating listings that take into account *all* relevant functional deficits, therefore, it is arbitrary to exclude an individual functional determination.

---

[32] Levine, *supra* note 20, at 947.

[33] In some cases, of course, procedural differences in the evaluation process do reflect different substantive eligibility standards. The truncated evaluation process available to widows and widowers, for example, which omits an assessment of residual functional capacity or consideration of vocational factors, is the result of a different underlying standard of disability. 42 U.S.C. § 423(d)(2)(B) (1982) requires a widow or widower to show inability to perform "any gainful activity," rather than, in the case of wage earners themselves, "any substantial gainful activity."

CONCLUSION

For the foregoing reasons, the judgment of the court of appeals should be affirmed.

Respectfully submitted,

LEONARD S. RUBENSTEIN
Mental Health Law Project
2021 L Street, N.W., Suite 800
Washington, D.C. 20036
(202) 467-5730

Counsel for *Amici Curiae*